

## Ontario Familial Colorectal Cancer Registry



### Follow-up Personal History Questionnaire

Four years ago, you completed a personal history questionnaire (PHQ) about factors that may relate to a person's risk of developing cancer. It is important to update this information and seek additional information for scientific research. We encourage you to answer **all** questions.

If you come to a question that you do not want to answer, please write "prefer not to answer" beside it and continue to answer the remaining questions. Should you wish to talk to someone about this questionnaire, you may call (416) 217-1310 or toll free 1-866-225-2728, or email us at OFCCR@cancercare.on.ca

	Surname				First na	ame	 Mi	ldle initial
						-	1.11	
t name	Street 1	et nam	ame and	and number			Apartment	:
ity	Town/City	City			Province/	/State		
e/Zip	Postal code/Z	de/Zip	Zip		Countr	try		
( <u> </u>	ber (home):		(Area o	rea code	·			
(	ber (work):	(	(	rea code				
will ko	1470 147	will ka	ll koon thi		ution confident	ntia <sup>1</sup>		
n the f	we wo	in the	he future	o this informat ture and you	ntion confident I have moved om we might	d, could	l we please	nave the ur new
n the f	contact you in	in the twing wi	he future g with yo	this informat ture and you you to whor	ı have moved	d, could	or call for y	nave the ur new
n the fing wi	contact you in ho is not living we or friend:	in the fiving wi	he future g with yo d):	this informat ture and you you to whor	ı have moved om we might	d, could	or call for y	our new
n the fing wi	contact you in ho is not living we or friend:	in the to ving with the control of t	he future g with yo d):	this informat ture and you you to whor	ı have moved om we might	d, could	or call for yo	our new
n the fing wi	contact you in tho is not living the or friend:g., sister, friend:	in the to ving with the ving w	he future g with yo d):	this informat ture and you you to whor	n have moved om we might	d, could twrite of	or call for yo	our new
n the fing with the field it name ity	contact you in ho is not living the or friend:g., sister, friend:Street in	in the fiving with the property of the propert	he future with your discount ame and discount di	this informat ture and you you to whor	Province/	d, could t write of	or call for yo	our new
n the fing with the fing with the field):	contact you in ho is not living the or friend:  g., sister, friend:  Street 1  Town/City	in the fiving wi	he future g with you d):ame and	and number	Province/	d, could t write of	Apartment	our new
n the fing with the fing with the fing with the fing with the find	contact you in ho is not living the or friend:	in the the ving wing wing wing wing wing wing wing w	he future g with you d):ame and	and number  and code  and code	Province/	d, could twrite of	Apartment	our new

		completed the PHQ, have you used an alternative healthcare provider, such as a apuncturist, herbalist, naturopath or massage therapist?
	0	yes please specify
	0	no
	0	don't know
Et	hnicity, Race,	Study, Address and Contact Information
67.	are more comme know if this is to	ce sometimes affect disease risk. Scientists have found that some genetic traits on or less common among people of different backgrounds. We would like to rue for genes associated with colorectal cancer. What is your ethnic or racial lease tick all that apply.
	0	Black
	0	White
	0	First Nations (e.g. Indian, Inuit)
	0	Latino/Hispanic (e.g. Spanish)
	0	Middle Eastern (e.g. Iranian)
	0	South East Asian (e.g. Chinese, Vietnamese, Korean, etc.)
	0	South Asian (e.g. East Indian, Pakistani)
	0	other please specify
	0	don't know
68.	Are you current	ly participating in any other genetic or family-based cancer studies?
	0	yes Please list all studies. Please use the back cover of this questionnaire if you need additional space.
	0	no
	0	don't know

Please write in your answers where space is provided, or place tick marks in circles  $\,\varnothing\,$ 

What date are you filling out this questionnaire?/day month year
<b>Identifying Information</b>
1. What is your age today? years
O don't know
2. What is your date of birth?
day
month
year
O don't know day
O don't know month
O don't know year
you last completed your personal history questionnaire. This date appears on the yellow sticked attached to the upper right corner of this questionnaire.  Bowel Screening, Personal Medical History
A test for <b>blood in your stool</b> is called <b>a smear test</b> or a <b>hemoccult test.</b> This test is done by usin specially treated cards and frequently done as part of a routine physical examination. It can also be done at home using a kit.
3. Since you last completed the PHQ, have you had a test for blood in your stool, called a sm test or a hemoccult test?
Please refer to the yellow sticker for the date when you completed the PHQ.
O yes
O no — please go to # 7
O don't know — please go to # 7
4. <b>Since you last completed the PHQ</b> , how many times have you had this test?
number of tests
O don't know

5.	When was <b>the most recent</b> test?  age at <b>most recent</b> test or	<b>During the past 4 weeks</b> , have you had any of the following problems with your work or other regular daily activities as a result of <b>any emotional problems</b> (such as feeling depressed or anxious)?
	year of most recent test or	all of the most of some of the time the time the time the time
	I had the <b>most recent</b> test years ago O don't know	58. Have you accomplished less O O O O O O than you would like?
6.	What were the reasons for <b>the most recent</b> test? <i>Please tick all that apply.</i> O to investigate a new problem  O family history of colorectal cancer	59. Did you work or perform O O O O O O O O other activities less carefully than usual?
	<ul><li>O routine examination or check-up</li><li>O follow-up of a previous problem</li></ul>	60. <b>During the past 4 weeks</b> , how much did pain interfere with your normal work, including both work outside the home and housework?
	O other <i>please specify</i> O don't know	O not at all O a little bit O moderately O quite a bit O extremely
7.	Endoscopy involves looking inside the bowel using a lighted instrument. There are two endoscopic procedures to examine the large bowel. A <b>sigmoidoscopy examines the lower bowel and rectum</b> and is usually done in a doctor's office <b>without</b> any medication. In a <b>colonoscopy, the entire large bowel is examined, using a long flexible instrument</b> . You are generally given medication to relax you or make you sleepy. In preparing for the colonoscopy, you will have had an enema or taken ½ to 1 gallon of liquid preparation, such as Golytely, Oral	These questions are about how you feel and how things have been with you <b>during the past 4 weeks</b> .  all of the most of the time some of the time a little of the time the time  61. Have you felt calm OOOOOOOOOOOOOOOOOOOOOOOOOOOOOOOOOOOO
	Fleets, Fleet PhospaSoda, Colyte, Magnesium Citrate or Klean-Prep, the day before the procedure to completely empty your bowels.	62. Did you have a lot of energy? O O O O
	Since you last completed the PHQ, have you had a sigmoidoscopy?  Please refer to the yellow sticker for the date when you completed the PHQ.  O yes	63. Have you felt downhearted O O O O O O and depressed?
0	O no — please go to # 11 O don't know — please go to # 11	64. Has your physical health or O O O O O O O emotional problems interfered with your social acitivities (like visiting friends, relatives
8.	Since you last completed the PHQ, how many times have you had a sigmoidoscopy?  number of tests	etc.)?
9.	O don't know  Since you last completed the PHQ, when did you have the most recent sigmoidoscopy?  age at most recent test or  year of most recent test or	<ul> <li>If you have ever been diagnosed with colon or rectal cancer, please go to # 66.</li> <li>65. Do you think your chance of getting colon (bowel) cancer is higher or lower than the average person of your age and sex? Please answer this question only if you have never had colon or rectal (bowel) cancer. We are very interested in your opinion.</li> </ul>
	I had the <b>most recent</b> test years ago O don't know	O much O somewhat O the same O somewhat O much lower lower higher higher

#### **Health Issues**

We	would now like to know about yo	our cu	rrent health	ı status					
52.	In <b>general</b> would you say your l	health	is:						
	O excellent	0 v	very good	0	good	0	fair	0	poor
53.	How much do you currently we pounds pounds kilograms  O don't know	or							
	owing is a list of activities you m th now limits you in these activi	_		typical es, limi a lot	•			,	ot limited
54.	Moderate activites such as moving pushing a vacuum cleaner, bowl playing golf	_	able,	0		0			0
55.	Climbing several flights of stair	S		0		0			0
	ing the past 4 weeks, have you har daily activities as a result of y	our <b>p</b>	hysical he	_	g problems			k or ot	her
		all of time	the most the	of time	some of the time	8	little of the time	no <sup>r</sup> th	ne of e time
56.	Have you accomplished less than you would like?	0	0		0		0		0
57.	Were you limited in the kind of work or other acitivities?	0	0		Ο		0		0

10.	What were the	reasons for <b>the most recent</b> sigmoidoscopy? <i>Please tick all that apply.</i>
	0	to investigate a new problem
	0	family history of colorectal cancer
	0	routine examination or check-up
	0	follow-up of a previous problem
	0	other please specify
	0	don't know
11.	Since you last	completed the PHQ, have you had a colonoscopy?
	Please refer to	the yellow sticker for the date when you completed the PHQ.
	0	yes
	0	no — please go to # 16
	0	don't know — please go to # 16
12.	Since you last	<b>completed the PHQ</b> , how many times have you had a colonoscopy?
	nu	mber of tests
	0	don't know
13.	Since you last	completed the PHQ, when did you have the most recent colonoscopy?
	ag	e at most recent test or
	ye	ar of <b>most recent</b> test or
	Ιh	and the <b>most recent</b> test years ago
	0	don't know
14.	What were the	reasons for <b>the most recent</b> colonoscopy? <i>Please tick all that apply.</i>
	0	to investigate a new problem
	0	family history of colorectal cancer
	0	routine examination or check-up
	0	follow-up of a previous problem
	0	other please specify
	$\circ$	don't know

15.	Where did you have <b>the most recent</b> colonoscopy?
	Name of physician Dr
	Hospital
	City/Town
	Province/State
	Country
	O don't know
16.	A <b>barium enema (BE)</b> is a x-ray examination of your colon. In this procedure, a barium solution, and usually air, is infused into the colon or bowel through the rectum, allowing thes organs to be seen on the x-ray.
	Have you ever had a barium enema?
	O yes
	O no — please go to # 22
	O don't know — please go to # 22
17.	How times have you had a barium enema?
	number of barium enemas
	O don't know
18.	When did you <b>first</b> have this test?
	age when first tested or
	year of <b>first</b> test <b>or</b>
	I had the <b>first</b> test years ago
	O don't know
19.	What were the reasons for <b>your first</b> test? <i>Please tick all that apply.</i>
	O to investigate a new problem
	O family history of colorectal cancer
	O routine examination or check-up
	O follow-up of a previous problem
	O other please specify
	O don't know

19.	When did you <i>first</i> have surgery on your uterus and/or ovaries?	W	hat type of surgery did you have the <i>first</i> time?	Where was this surger performed?
	age at surgery	0	hysterectomy (only the uterus or womb removed)	Name of surgeon
	year of surgery	0	hysterectomy with ovary or part of an ovary removed	Hospital/Clinic
	the surgery was years ago	0	hysterectomy with both ovaries removed	Town/City
	O don't know	0	one ovary removed, completely, or partly, without hysterectomy	Province/State
		0	both ovaries removed without hysterectomy	Country
		0	other, specify	
		0	don't know	O don't know
	Since you last completed the PHC ovaries?  Please refer to the yellow sticker for yes  O yes  O no please		e date when you completed the l	РНQ.
51.	ovaries?  Please refer to the yellow sticker for yes  on no please on don't know  When did you next have surgery	e go t	te date when you completed the factor # 52 please go to # 52 That type of surgery did you	Where was this surger
51.	ovaries?  Please refer to the yellow sticker for one with the	e go t	to # 52  That type of surgery did you have the next time?  hysterectomy (only the uterus	
51.	ovaries?  Please refer to the yellow sticker for yes  on no please on don't know  When did you next have surgery on your uterus and/or ovaries?	e go t	to # 52  Chat type of surgery did you have the next time?	Where was this surger performed?
51.	ovaries?  Please refer to the yellow sticker for yes  O no please O don't know  When did you next have surgery on your uterus and/or ovaries?  age at surgery	e go t	to # 52  That type of surgery did you have the next time?  hysterectomy (only the uterus	Where was this surger performed?
51.	ovaries?  Please refer to the yellow sticker for year of yellow sticker for year of yellow sticker for yellow ye	e go i	to # 52  That type of surgery did you have the next time?  hysterectomy (only the uterus or womb removed)  hysterectomy with ovary	Where was this surger performed?  Name of surgeon
51.	ovaries?  Please refer to the yellow sticker for year of yellow sticker for year of yellow sticker for yellow ye	w O	to # 52  That type of surgery did you have the next time?  hysterectomy (only the uterus or womb removed)  hysterectomy with ovary or part of an ovary removed hysterectomy with both	Where was this surger performed?  Name of surgeon  Hospital/Clinic
51.	ovaries?  Please refer to the yellow sticker for yellow yel	<b>w</b> ○ ○	to # 52  Chat type of surgery did you have the next time?  hysterectomy (only the uterus or womb removed)  hysterectomy with ovary or part of an ovary removed hysterectomy with both ovaries removed one ovary removed, completely, or partly,	Where was this surger performed?  Name of surgeon  Hospital/Clinic  Town/City
51.	ovaries?  Please refer to the yellow sticker for yellow yel	• go i	to # 52  That type of surgery did you have the next time?  hysterectomy (only the uterus or womb removed)  hysterectomy with ovary or part of an ovary removed hysterectomy with both ovaries removed one ovary removed, completely, or partly, without hysterectomy both ovaries removed without	Where was this surger performed?  Name of surgeon  Hospital/Clinic  Town/City  Province/State
51.	ovaries?  Please refer to the yellow sticker for yellow yel	w 0 0 0 0 0	to # 52  That type of surgery did you have the next time?  hysterectomy (only the uterus or womb removed)  hysterectomy with ovary or part of an ovary removed hysterectomy with both ovaries removed one ovary removed, completely, or partly, without hysterectomy  both ovaries removed without hysterectomy	Where was this surger performed?  Name of surgeon  Hospital/Clinic  Town/City  Province/State

#### Men: please go to # 52; Women: please continue

#### **Female Hormones and Surgery**

46. Since you last completed the PHQ, have you taken an estrogen pill or used a patch, alone or in combination with another hormone continuously for at least 6 months? Please do not include hormone therapy that was prescribed for birth control, infertility or hormonal therapy delivered by injections, vaginal creams or suppositories or herbal or soy products.

Please refer to the yellow sticker for the date when you completed the PHQ.



47. **Since you last completed the PHQ**, (please refer to the yellow sticker for the date when you completed the PHQ), how long, in total did you take any of these preparations containing estrogen (alone or in combination)? If you started and stopped and then started again, please count only the time you were taking this medication.

number of <b>months</b>	0
number of years	
O don't know	

Since you last completed the PHQ, have you had any surgery to remove your reproductive organs, such as uterus (hysterectomy), and/or ovaries?

Please refer to the yellow sticker for the date when you completed the PHQ.

0	yes
0	no — please go to # 52
0	don't know — please go to # 52

20. When did you have **the most recent** barium enema? age at **most recent** test \_\_\_\_\_ or year of most recent test \_\_\_\_ \_\_ or I had the **most recent** test \_\_\_\_\_\_ years ago O don't know 21. What were the reasons for **the most recent** barium enema? *Please tick all that apply.* O to investigate a new problem O family history of colorectal cancer O routine examination or check-up O follow-up of a previous problem other please specify \_\_\_\_\_ O don't know 22. A virtual colonoscopy or colonograph uses a CAT Scan (CT) or Magnetic Resonance Imaging

(MRI scan) to create an image of the colon. This procedure is not widely available at this time, but is used on an experimental basis in some parts of the province. Virtual colonoscopy is often done in combination with another test like sigmoidoscopy or colonoscopy.

Have you ever had a virtual colonoscopy or colonograph?

0	yes
0	no
0	don't know

23. Since you last completed the PHQ, has a doctor told you that you had polyps in your large bowel or colon or rectum? Please think about all polyps that were found in any of the procedures you had since you last completed the PHQ.

Please refer to the yellow sticker for the date when you completed the PHQ.

0	yes
0	no — please go to #31
0	don't know — please go to # 3.

24. Were any of these polyps **removed**?

0	yes
0	no — please go to #31
0	don't know — please go to #3

25.	On how many sepa	rate occasions we	re these polyps re	emoved?	
		number of tin	nes polyps were i	removed	
	O do:	n't know			
26.	Since you last com	pleted the PHQ,	when did you fir	st have polyps remov	red?
	age pol	yp removed	or		
	year po	olyp removed		or	
	remove	ed years a	ago		
	O do:	n't know			
27.	Since you last comply lf polyps were not re			te polyps removed the $p \# 30$ .	e second time?
	age pol	yp removed	or		
	year po	olyp removed		or	
	remove	ed years	ago		
	O do:	n't know			
28.	Since you last comply If polyps were not re			ve polyps removed th # 30.	e <b>third</b> time?
	age pol	yp removed	or		
	year po	olyp removed		or	
	remove	ed years a	ago		
	O do:	n't know			
29.	Since you last comply If polyps were not re			we polyps removed th # 30.	e <b>fourth</b> time?
	age pol	yp removed	or		
	year po	olyp removed		or	
	remove	ed years a	ago		
	O do:	n't know			
30.	Where were the poly	moved	Polyps removed	Polyps removed	Polyps removed
		Polyps rent time the first time	PolyPs remove the second time	Polyps remove the <b>third</b> time	Polyps remove the <b>fourth</b> time
Na	me of Physician		· · ·		· · ·
	ospital/Clinic			_	
	y/Town, Province/State			_	
	untry			_	
		O don't know	O don't know	v O don't know	O don't know

#### Please use the back cover of this questionnaire if you need additional space.

# Sun Exposure

45. Please answer the following questions about your exposure to the sun during different periods of your life. Please include all sun exposure **at work** and **in your leisure time**.

	On a typical weekday in the summer (May-September), about how many hours per day did you spend outside in the sun?	On a typical weekend (Saturday and Sunday) in the summer (May–September), about how many hours per day did you spend outside in the sun	When in the sun, did you wear <b>sunscreen or protective clothing</b> such as long sleeves etc.?		e place(s) ou have year?
less than 1 hour 1 to 2 hours 3 to 4 hours more than 4 hours don't know	ur hours	<ul> <li>O less than 1 hour</li> <li>O 1 to 2 hours</li> <li>O 3 to 4 hours</li> <li>O more than 4 hours</li> <li>O don't know</li> </ul>	O never O sometimes O always O don't know	City/Country	no. of years
less than 1 hour 1 to 2 hours 3 to 4 hours more than 4 hours don't know	our s s 4 hours	<ul> <li>O less than 1 hour</li> <li>O 1 to 2 hours</li> <li>O 3 to 4 hours</li> <li>O more than 4 hours</li> <li>O don't know</li> </ul>	O never O sometimes O always O don't know	City/Country	no. of years
less than 1 hour 1 to 2 hours 3 to 4 hours more than 4 hours don't know	ur hours	O less than 1 hour O 1 to 2 hours O 3 to 4 hours O more than 4 hours O don't know	O never O sometimes O always O don't know	City/Country	no. of years
O less than 1 hour O 1 to 2 hours O 3 to 4 hours O more than 4 hours O don't know	our s s 4 hours	O less than 1 hour O 1 to 2 hours O 3 to 4 hours O more than 4 hours O don't know	O never O sometimes O always O don't know	City/Country	no. of years

#### Medications

44. **Since you last completed the PHQ**, have you ever taken any of the following medications regularly (at least twice a week for more than a month)?

Please refer to the yellow sticker for the date when you completed the PHQ.

Medication	Since you last completed the PHQ, have you taken this medication <b>regularly</b> , i.e. at least twice a week for more than a month?	Since you last completed the PHQ, <b>how often</b> did you usually take it when you were taking it <b>regularly</b> ? (that is, at least twice a week for more than a month)	Since you last completed the PHQ, how long in total have you taken this medication regularly? If you started and stopped, then started again, please count only the time you were taking this medication.
	Please tick only one category for each medication	Please tick only one category for each medication	Please tick only one category for each medication
ASPIRIN (such as Anacin, Bufferin; Bayer, Excedrin, etc.)	O yes O no O don't know	times per daytimes per week O don't know	months years O don't know
ACETAMINOPHEN (such as Tylenol, Anacin-3, Panadol, etc.)	O yes O no O don't know	times per daytimes per week O don't know	months years O don't know
NSAIDS - Non steroidal anti-inflammatory drugs (such as Advil, Aleve, Motrin, Nuprin, Medipren, Indocid, Naprosyn, Sulindac, Clinoril)	O yes O no don't know	times per daytimes per week O don't know	months years O don't know
COX 2 Inhibitor NSAIDS (such as Celebrex, Vioxx, Mobicox.)	_	times per daytimes per week O don't know	months years O don't know
MULTIVITAMIN SUPPLEMENTS (such as One-A-Day, Centrum, Unicap). <b>Not</b> individual vitamins.	O yes O no O don't know	times per daytimes per week O don't know	months years O don't know
FOLIC ACID or FOLATE pills or tablets	O yes O no O don't know	times per daytimes per week O don't know	months years O don't know
CALCIUM pills or tablets	O yes O no O don't know	times per daytimes per week O don't know	months years O don't know
CALCIUM BASED ANTACIDS (such as Tums, Rolaids, Extra- strength Rolaids, Alkamints, Chooze antacid gums)	O yes O no O don't know	times per daytimes per week O don't know	months years O don't know

	<b>Since you last completed the PHQ</b> , have you had any surgery to remove any part of your large bowel or colon? Please do <b>not</b> include any surgeries where <b>only polyp(s)</b> were removed.					
Please refer t	Please refer to the yellow sticker for the date when you completed the PHQ.					
	O yes O no — please go to # 34					
	O don't know — plea.	se go to # 34				
32. Since you las	t completed the PHQ, how m	nany times have you had this	surgery?			
-	number of times you had this s					
	O don't know					
•	et completed the PHQ (please PHQ), when was the:	e refer to the yellow sticker fo	or the date when you			
	First time you had this surgery?	Second time you had this surgery?	Third time you had this surgery?			
	age at surgery  or year of surgery or I had surgery years ago O don't know	age at surgery  or year of surgery  or I had surgery years ago O don't know	age at surgery or year of surgery or I had surgery years ago O don't know			
Your colon was removed	O partially O completely O don't know	O partially O completely O don't know	O partially O completely O don't know			
Reason for this surgery was	O diverticulitis O ulcerative colitis O inflammatory bowel disease O Crohn's disease O cancer O other, specify O don't know	O diverticulitis O ulcerative colitis O inflammatory bowel disease O Crohn's disease O cancer O other, specify O don't know	O diverticulitis O ulcerative colitis O inflammatory bowel disease O Crohn's disease O cancer O other, specify O don't know			
Place of surgery	Name of surgeon  Hospital/Clinic  Town/city  Province/State  Country	Name of surgeon  Hospital/Clinic  Town/City  Province/State  Country	Name of surgeon  Hospital/Clinic  Town/City  Province/State  Country			

O don't know

O don't know

O don't know

34.	Since you last completed the PHQ, has a doctor told you that you had any type of cancer?  Please refer to the yellow sticker for the date when you completed the PHQ.	40. Since you last completed the PHQ, has a doctor told you that you had any other to cancer?	type of
	O yes	O yes	
	O no — please go to # 43	O no — please go to # 43	
	O don't know — please go to # 43	O don't know — please go to # 43	
35.	What type of cancer was it?		
	cancer		
	O don't know	41. What type of cancer was it?	
36.	Since you last completed the PHQ, when did the doctor first tell you that you had this type of cancer?	O don't know	
	age at diagnosis or		
	year of diagnosis or		
	it was <b>diagnosed</b> years ago	40 Ct	
	O don't know	42. <b>Since you last completed the PHQ</b> , when did the doctor tell you that you had this cancer?	type of
37.	Since you last completed the PHQ, has a doctor told you that you had any other type of	age at diagnosis or	
	cancer?	year of diagnosis or	
	O yes	it was <b>diagnosed</b> years ago	
	O no — please go to # 43	O don't know	
	O don't know — please go to # 43		
38.	What type of cancer was it?		
	O don't know	43. Have you <b>ever</b> had a blood test to look for genes for colorectal cancer as part of yo care? <i>Please</i> <b>do not include</b> it if you had a blood test as a part of this or another re study.	
39.	Since you last completed the PHQ, when did the doctor tell you that you had this type of	O yes	
	cancer?	O no	
	age at diagnosis or	O don't know	
	year of diagnosis or		
	it was <b>diagnosed</b> years ago		
	O don't know		